

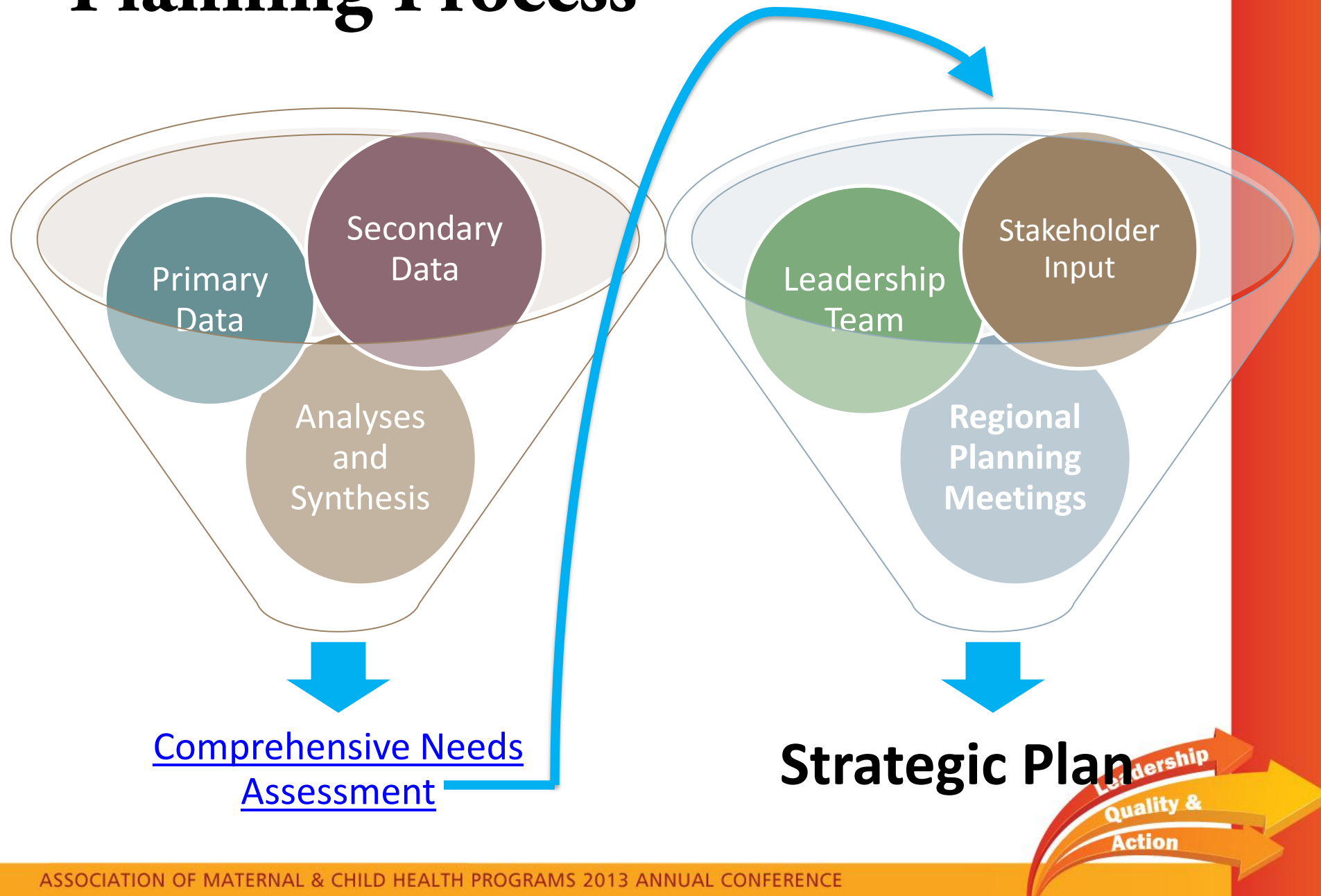


The Role of Data in Maryland's Planning Grant for Children and Youth with ASD/DD

Meredith Pyle, *Maryland Office for Genetics and
People with Special Health Care Needs*

Josie Thomas, *The Parents' Place of Maryland*

Planning Process



Challenges

- Synthesis (almost too MUCH data)
- Making data meaningful to stakeholders (multiple audiences)
- Competing interests and priorities; turf issues among leadership team
- Lack of trust from some parents



What worked for us

- Extensive parent and stakeholder involvement throughout process (we had to make this happen!)
- Lots of data; taking the time to analyze and translate it (had to make it meaningful!)



The background image shows two children standing on a sandy beach, looking out at the ocean. A dark, low-profile fence or barrier is positioned between the children and the water. The ocean waves are visible in the background. The image is used as a backdrop for a list of survey and assessment programs.

NS-CSHCN

Kids Count

Waiver Survey

US Census

ADDM

Other Needs
Assessments

State Special
Education

Parent Survey

What we had to start with:

National Sources

- [National Survey of CSHCN](#) (E/B/D subgroup)
- [2011 Survey of Pathways to Diagnosis and Services](#)
- [Autism and Dev. Disabilities Monitoring \(ADDM\)](#)
- [SAHIE](#)
- [SAIPE](#) and [Kids Count](#)

State and Local Sources

- [Title V 2010 Needs Assessment](#)
- [2010 Maryland Parent Survey](#) (n= 293 ASD; N=778 CSHCN)
- [State Special Education Census](#)
- Maryland Autism Services Survey
- [Maryland Commission on Autism](#)
- [Maryland Center for Developmental Disabilities](#) Needs Assessment
- Title V and [PPMD](#) Program Data



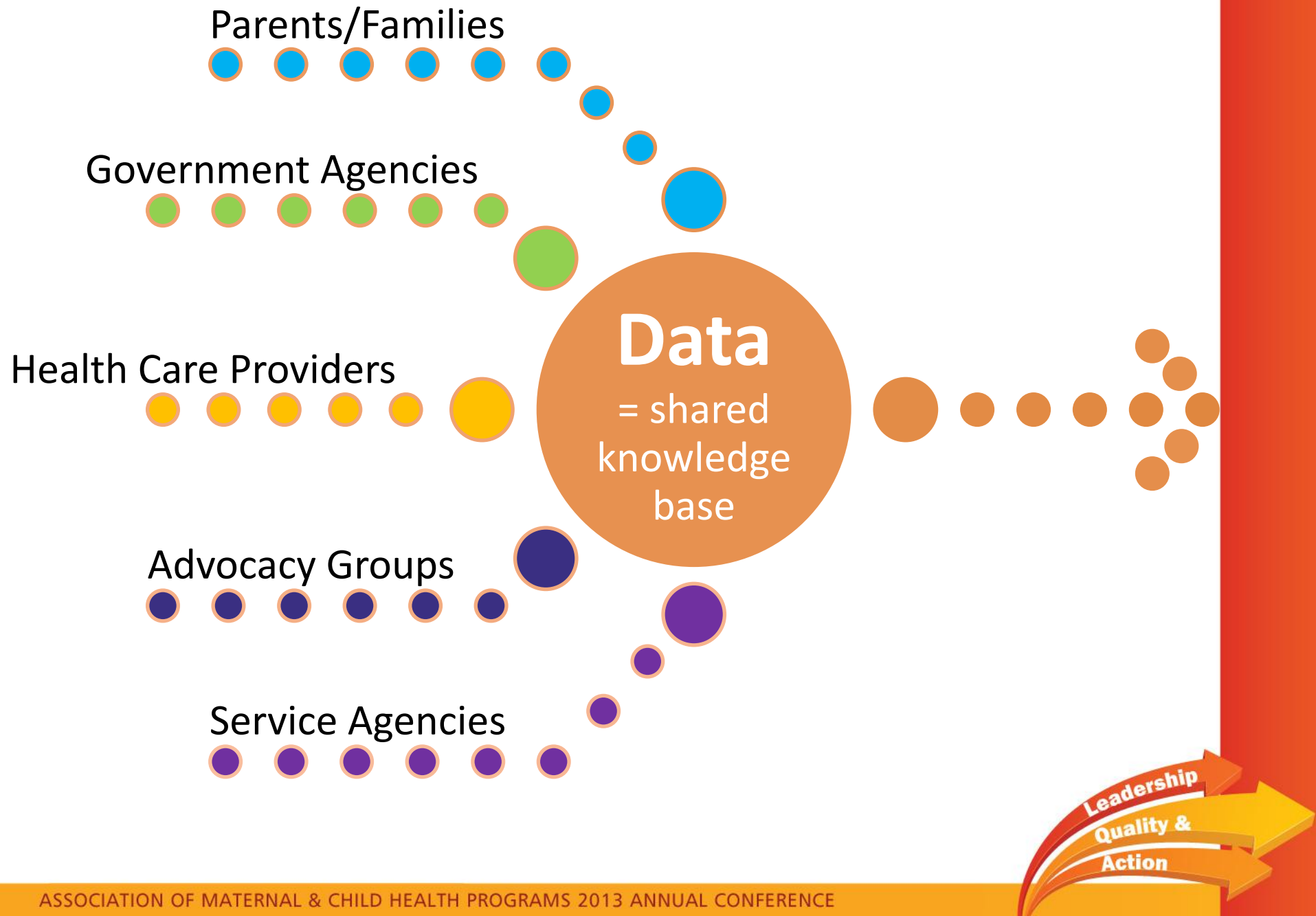
SUCCESS!

What we had to go out and get:

- Additional analysis of 2010 Maryland Parent Survey
- Parent Focus Groups – low income; non-English (Spanish) speaking; rural regions
- Stakeholder Survey to identify potential top priorities
- Extensive stakeholder input from every region of the state

SUCCESS!

Leadership
Quality &
Action



Conclusion

We used data to:

- (1) assess needs; and
- (2) create a foundation for stakeholder cohesiveness

- it created a shared knowledge base from which to prioritize and plan

Stakeholders are using the ASD/DD Needs Assessment for their own purposes

- Sharing with other partners
- Grant writing
- Talking to legislators



For more information:

- Use the hyperlinks in these slides
- Visit:

http://marylandcoc.com/ASD_DD_Planning_Grant.html

THANK YOU!



The Role of Data in Building, Implementing and Evaluating Systems of Care for Children and Youth with ASD/DD


JUDITH M.HOLT, PHD

**ASD PROJECT CO-
DIRECTOR AT UTAH
STATE UNIVERSITY**

URLEND CO-DIRECTOR

**UTAH ASD/DD SYSTEMS DEVELOPMENT
PROJECT (2008 -2012)**

**USING EVALUATIVE DATA TO
INFORM AND EXTEND THE
ASD/DD SYSTEMS
DEVELOPMENT PROJECT**

- Briefly describe the major activities
 - Data collection procedures
 - Results
 - Application to the current ASD/DD system
- 

MAJOR ACTIVITIES

1. MEDICAL HOME ASD SCREENING COLLABORATIVES—pediatrics, family practice, pediatric dentists, and allied health professionals

Types of collaboratives:

- (a) 6 month collaborative with group training,
- (b) An in office / peer mentored approach, and
- (c) Distance-learning collaborative

- MEDICAL HOME MODEL
- M-CHAT AT 18 AND 24 MONTHS

Evaluative Methodology

Learning sessions evaluations, pre-post surveys, monthly progress reports, site visits and project summaries.

Results

- Pediatric practices (24) and family practices (8)
- Baseline: varied from 5% to 35% rates of autism screening at 18 and 24 months
- Post – project: 84% - 96%

Pediatric screening for ASD is used more widely in the state.

Dental Practices

- Behavior Management Techniques

MAJOR ACTIVITIES (con't)


2. Improve the quality and accessibility of ASD/DD-related resources for families and professionals through expanding the Utah Medical Home Portal website www.medicalhomeportal.org

- FY2011, 99,049 total users and 5,363 viewed ASD pages.
- ASD pages were in the top 20 all three years and were #8 in FY2011.
- FY2011, there were 163 referrals from Autism-related Organization web-sites

Utah Medical Home website has continued to actively expand it's ASD content and resources and has increasing use in Utah and across the nation.

MAJOR ACTIVITIES (Cont')

3. Improve capacity of community-based human services providers and educators to recognize early signs and see early diagnostic and treatment services.
4. Improve number of referrals and timely screening for ASD in a 3 (urban / rural mix) counties

- Provided Act Early materials to medical, health, and child care, early childhood, and early intervention providers.
 - Multiple onsite presentations and office visits.
- 

Implemented specific procedures in an early intervention program (birth to 3) to screen children referred for services in a more timely manner

- Trained staff in ASD characteristics in young children using Act Early materials
- Added two questions to intake-“Does either parent have a family history of Autism?”
- “Have you or anyone who knows your child been concerned with Autism?”

- 2011—432 referrals (increase from 373 based primarily on increased Act Early activities)
- Physician referrals increased by 7% and families by 8.5%
- Eligible for ASD services increased from 9% to 18%
- More identified at intake; fewer identified after initial IFSP

APPLICATION

Recommended adoption of procedures by other early intervention programs

MAJOR ACTIVITIES (Cont')

- “Autism ABCs-for caregivers”
- Initially developed by URLEND trainees and faculty as a 3 hours per week for 6 weeks workshop
- State Team members adapted for use by a broader group of trainers and also adapted for Spanish-speaking families

- Evaluation of participant satisfaction were 4.5 / 5.
29 trainings(4 in Spanish) and 537 participants.
- ABCs is still being used by a number of ASD parent groups (including Spanish-speaking groups) and by the CSHCN Bureau.

Lagniappe

- Act Early Ambassador
- Statewide Survey regarding public awareness of ASD
- MCHB/CDC Targeted Public Awareness
- HCBS ASD Pilot Waiver and Health Department Pilot

Statewide ASD Survey

- The purpose of this study was to identify public awareness and knowledge of ASD in Utah.
- Published 2013 Disability and Health Journal, (6)1:52-62.

Contact Information

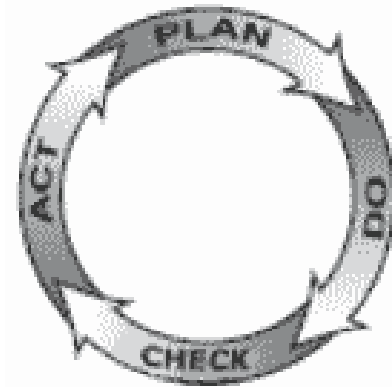
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Utah State University
Logan, UT 84322-6880
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Using Data to Influence Policy

Adventures in Autism Systems Change

Nancy Cronin, MA
Maine Developmental Disabilities Council



Ready?

Get Set...

Go

Ready?

Types of Data

Programmatic Process Reports

- How many steps?
- How many plans?
- How long did it take?

Demographic

- How many? Where do they live?
- Gender?
- What co-morbid disabilities?
- How do we compare to national?

Service Reports

- What services are being provided?
- How much does it cost?
- What does the national data say is evidence based?



Levels of Data Usage

Legislature

- Motivation

Stakeholders – Buy In

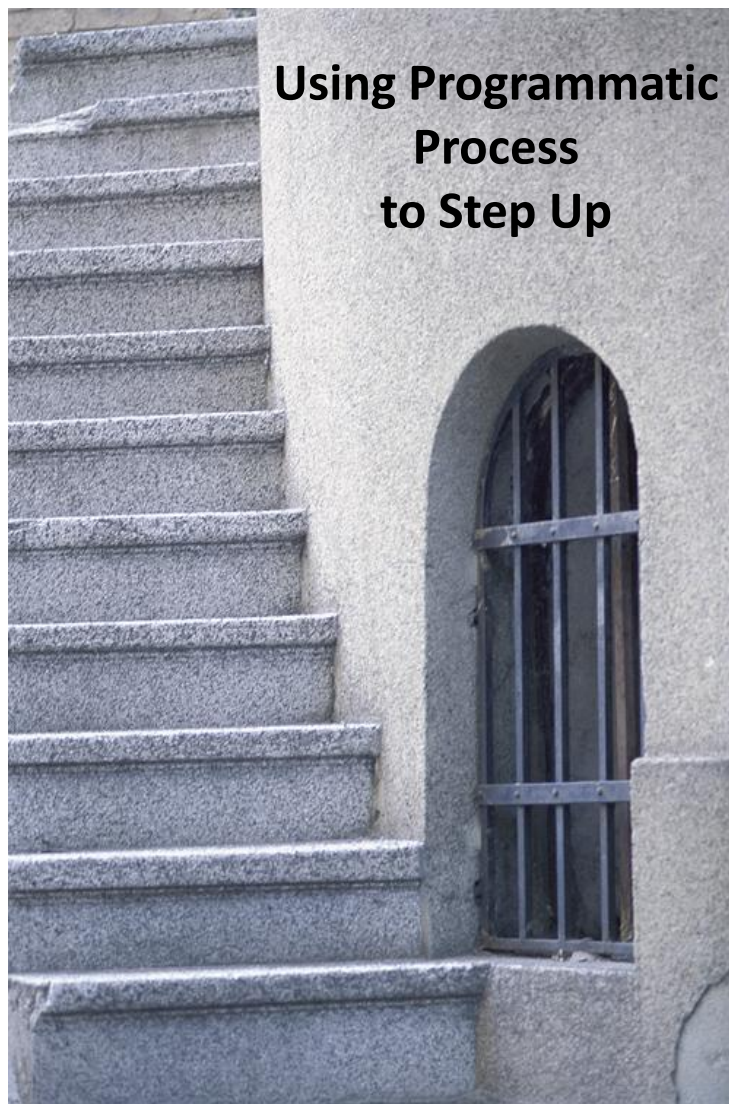
- Programmatic Process

Lead Policy Makers

- Cost Analysis
- Programmatic Process
- National Data
- Co-Morbid Data

Legislature

- Demographic
- National Data
- Co-Morbid Data
- More Motivation



Legislature – Motivation (Ready?)



Department of Health
and Human Services

*Maine People Living
Safe, Healthy and Productive Lives*

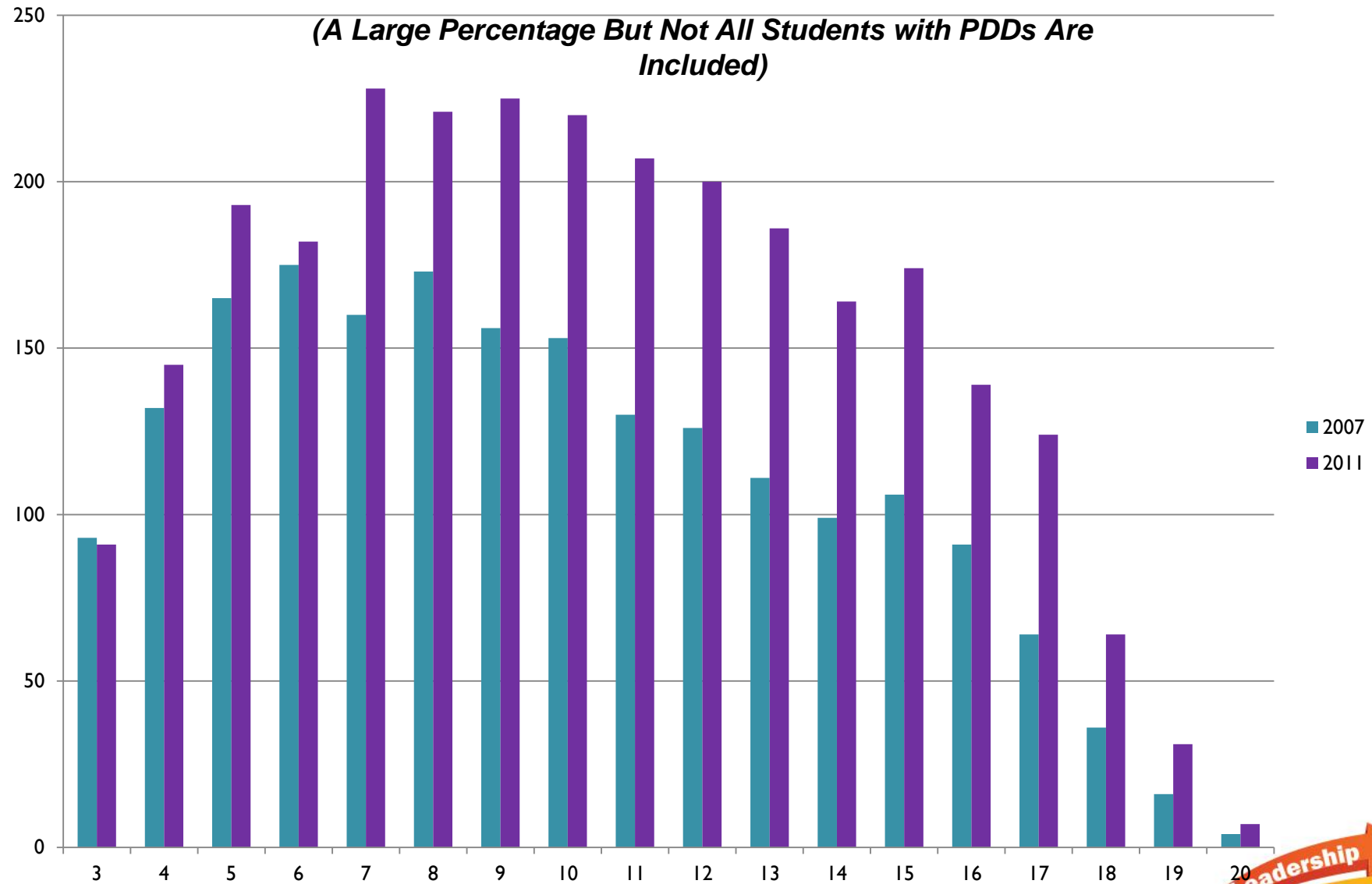
Autistic Spectrum Disorders Report

In response to legislative directive:
The Autism Act of 1984, 34-B M.R.S.A. §6001



Growth in # of Students Served By Maine Public Schools in Autism Category

(A Large Percentage But Not All Students with PDDs Are Included)

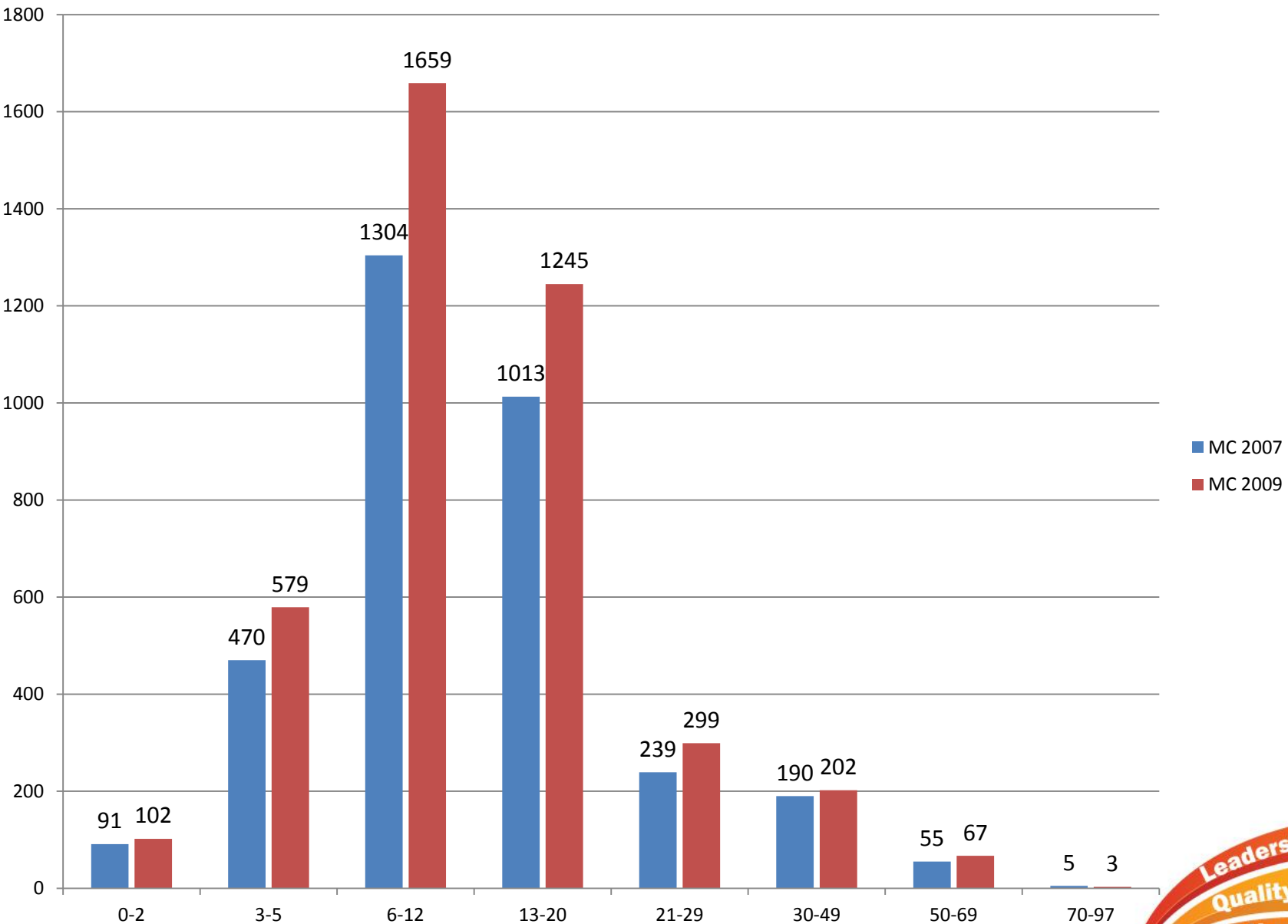


Source: Maine DOE ChildCount

Prepared by: Maine Developmental Disabilities Council



MaineCare Members diagnosed with a ASD for whom claims were paid



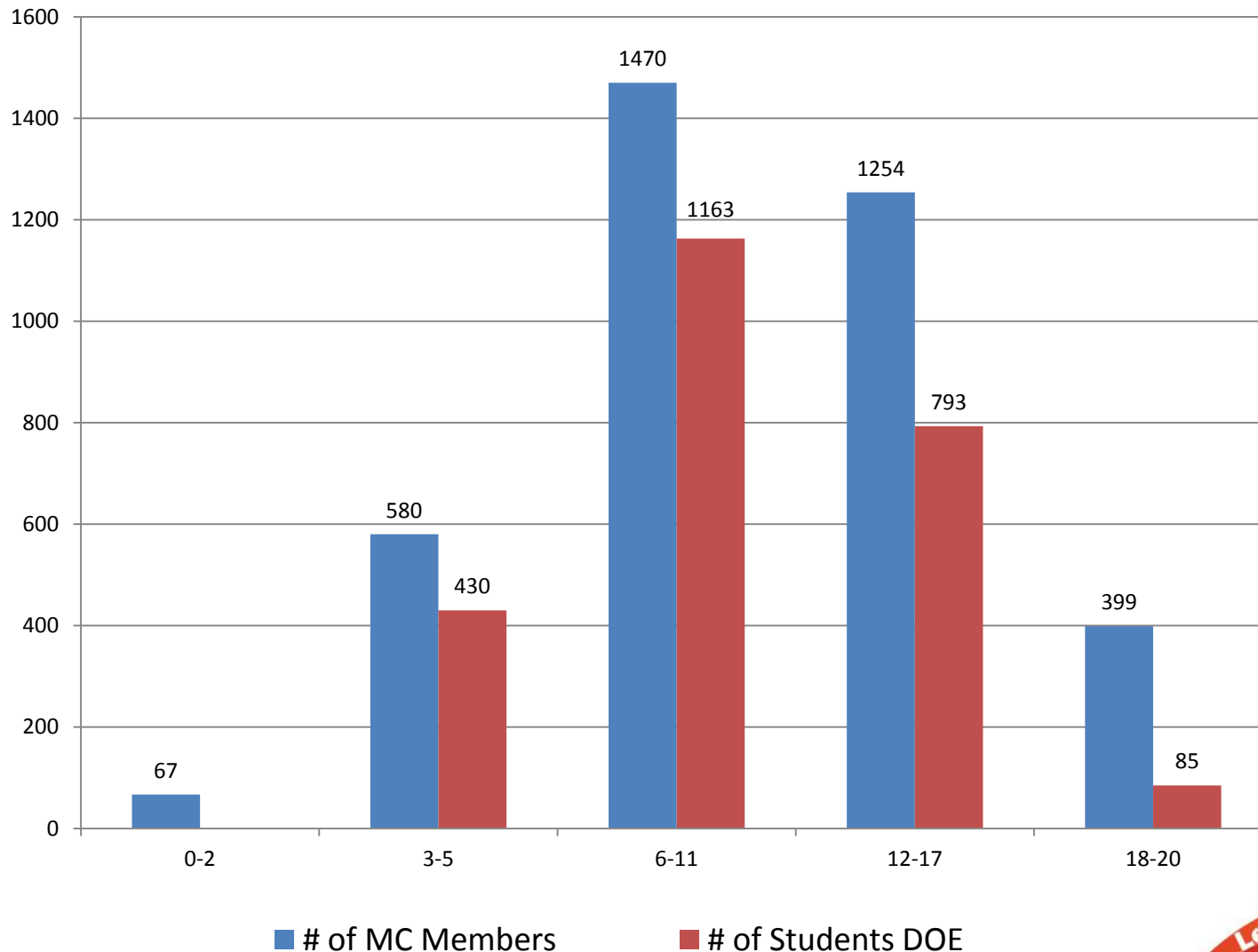
Data Source: Maine DHHS, Office of MaineCare Services

Prepared By: Maine Developmental Disabilities Council

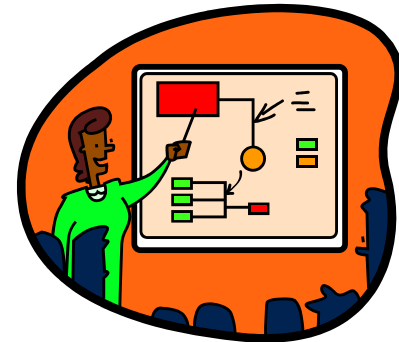


Distribution of Children with Autism or other ASDs Receiving Services through DOE and MaineCare

(MaineCare FY 2009 and DOE Dec 1, 2009 ChildCount)



Programmatic Data (Get Set...)



- Baseline Planning
- Multi-Level Stakeholders Designed
- Builds buy in from ground up
- Informs what real change would look like
- Eliminates political barriers by setting the stage for inclusion





Involved All Stakeholders (Public and Private, Individual and Professional)

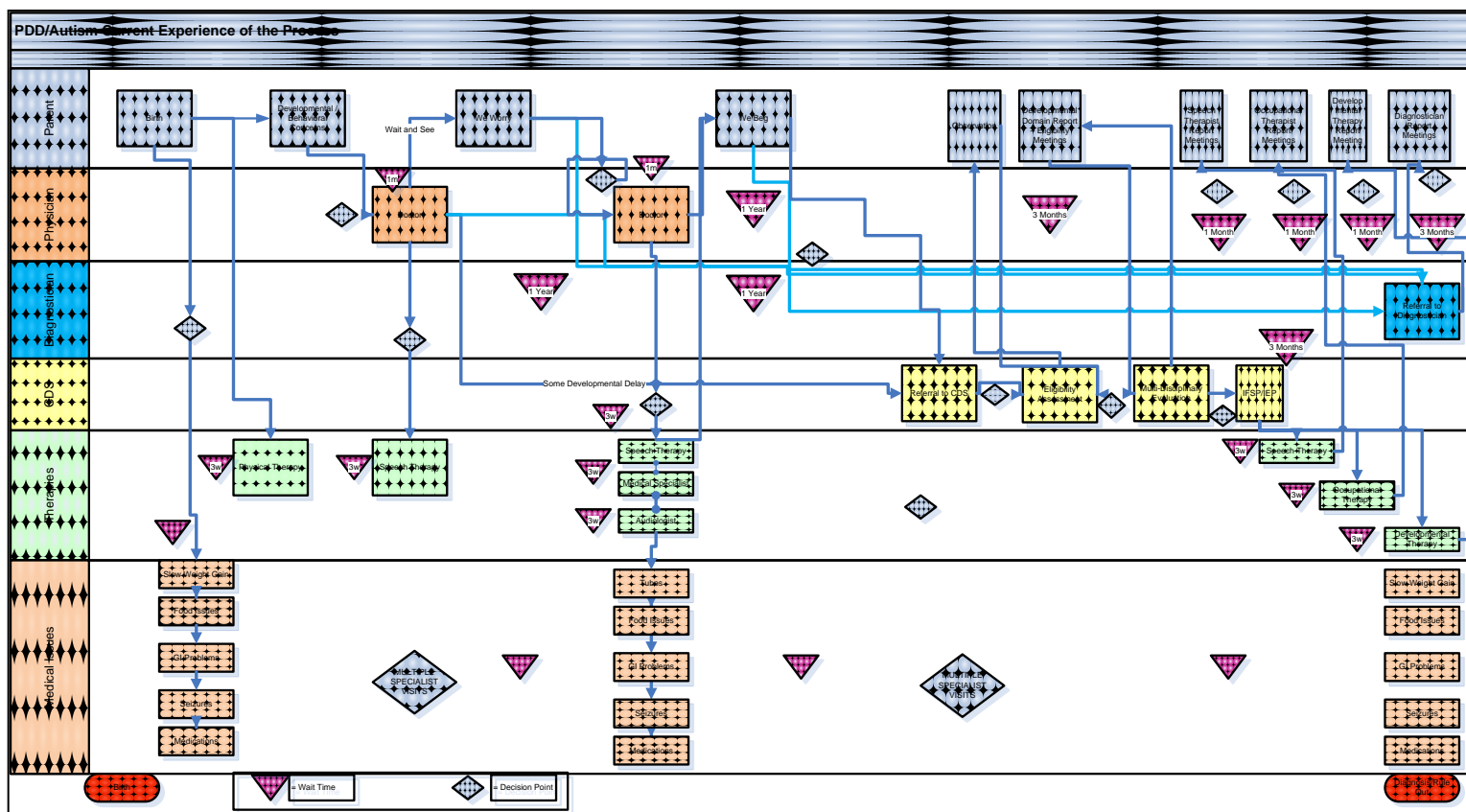
- DHHS Division of Early Childhood
- Child Developmental Services
- Psychologists
- Developmental Evaluation Clinics
- Medical Professionals
- Early Childhood Educators
- Child Care Providers
- Office of MaineCare Services
- Children with Special Health Needs
- Autism Society of Maine
- DHHS Children's Behavioral Health Services
- Disability Rights Center
- Parents
- Department of Education
- Speech and Occupational Therapists
- Center for Community Inclusion and Disabilities Studies
- Developmental Disabilities Council
- State Office of Information Technology
- Over 200 individuals with PDD, family members, & professionals as commenters





DRILL DOWN

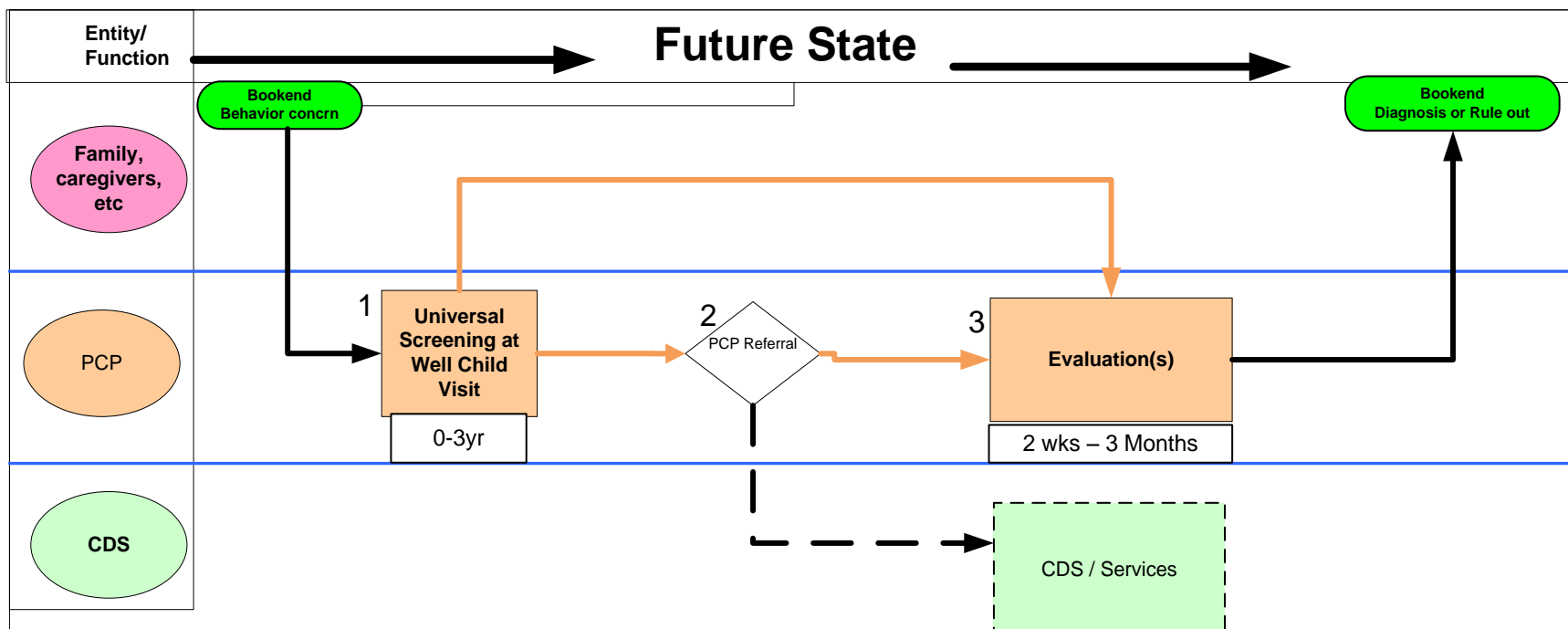
Early Identification Value Stream Mapping



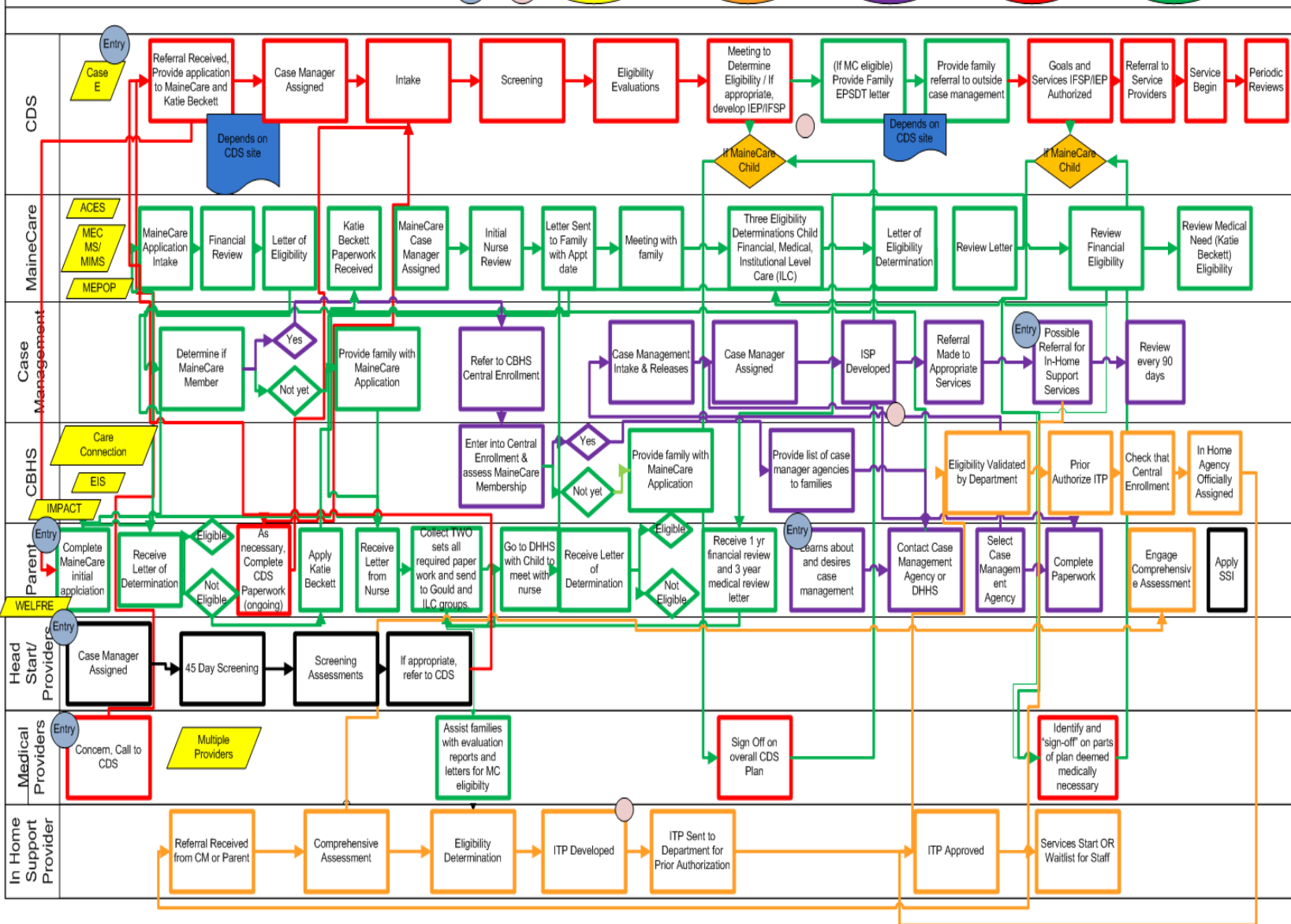
**Leadership
Quality &
Action**



Workgroup Future Map



Early Intervention System



Action

Evaluate Service Usage

| Highlights of Services Utilized by Children with PDD | | | | | | |
|---|---------------|-----------------|---------------|-----------------|-------------------|------------|
| Total number of Children identified as having a PDD - 3585 | | | | | | |
| Policy Section | 07 Members | 07 Total Paid | 09 Members | 09 Total Paid | Usage Increase | % of Whole |
| 013-Targeted Case Management Services | 2239 | \$7,942,937.81 | 2690 | \$8,544,800.71 | 20.1% | 75% |
| 017-Community Support Services | 32 | \$204,190.89 | 46 | \$514,375.40 | 43.8% | 1% |
| 024-Day Habilitation Services for Persons with MR | 828 | \$13,319,894.28 | 1057 | \$16,976,474.22 | 27.7% | 29% |
| 025-Dental Services | 1256 | \$352,617.00 | 1706 | \$585,652.19 | 35.8% | 48% |
| 027-Early Intervention Services | 476 | \$8,485,643.08 | 580 | \$11,020,153.97 | 21.8% | 16% |
| 031-Federally Qualified Health Centers & Rural Health Clinics | 1004 | \$568,879.10 | 1300 | \$736,251.10 | 29.5% | 36% |
| 041-Day Treatment Services | 516 | \$6,339,102.06 | 614 | \$8,127,285.32 | 19.0% | 17% |
| 002-INPATIENT PSYCH | 289 | \$16,701,226.63 | 346 | \$13,448,086.19 | 19.7% | 10% |
| 065-Behavioral Health Services | 1356 | \$6,676,975.33 | 1511 | \$6,206,559.38 | 11.4% | 42% |
| 090-Physician Services | 2296 | \$1,338,023.04 | 2701 | \$979,474.76 | 17.6% | 75% |
| 104-School Based Rehabilitative Services | 1428 | \$2,461,052.91 | 1765 | \$3,214,710.89 | 23.6% | 49% |
| 109-Speech and Hearing Services | 555 | \$753,743.39 | 688 | \$914,554.48 | 24.0% | 19% |
| 113-Transportation Services | 735 | \$1,475,799.40 | 991 | \$1,779,124.33 | 34.8% | 28% |

Leadership

Quality &

Action

MaineCare Service Data for Children

Data Highlights

- From 2007 to 2009 there was an overall increase in service usage by children with ASD:
 - 43.8% increase in Community Services
 - 29.5% increase in numbers served by Federally Qualified Health Centers and Rural Health Clinics
 - 27.7% increase in children and youth receiving in-home supports through former Section 24
 - 19.7% increase in number of children who received services in a psychiatric facility
 - 21.8% increase in early intervention services (formerly section 27)
- 75% of children with ASD are receiving Targeted Case Management
- 72% of children with ASD receive in-home/community supports through Children's Behavioral Health Services (Sections 24 and 65)
- 36% of children with ASD receive services through Federally Qualified Health Centers and Rural Health Clinic Services
- 66% of children with ASD receive school-based services (either through the former Section 41 or 104)



Policy Makers (GO!)

- ✓ Field Test of the Screening Tools (in 7 medical practices – over 3,500 children screened)
- Creation, by Developmental Pediatricians, Parents and Advocates, of a DVD and supporting train-the-trainer curriculum (Over 500 distributed)
- Over 150 Medical Professionals attend early screening presentations
- ✓ Medical Home Care Coordination Pilot
- ✓ Early Childhood/Physician Pilot





Programmatic Measurement (Example)

Chart A: Children diagnosed referred with suspicion of as having an ASD By Age (n=112)

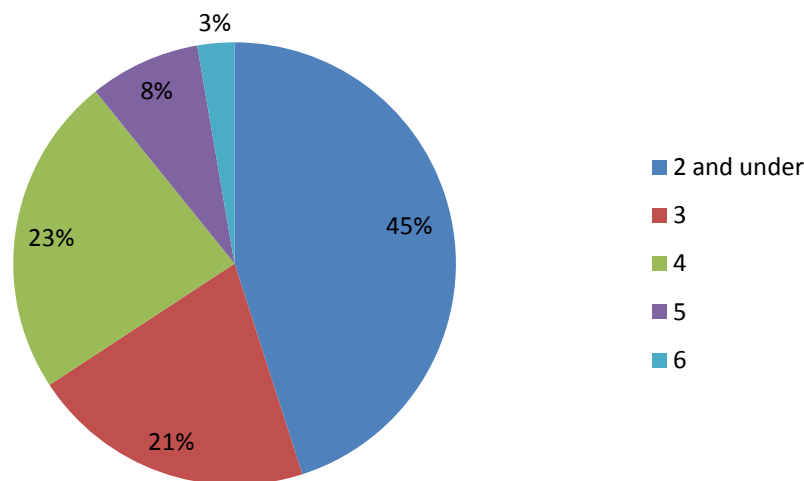
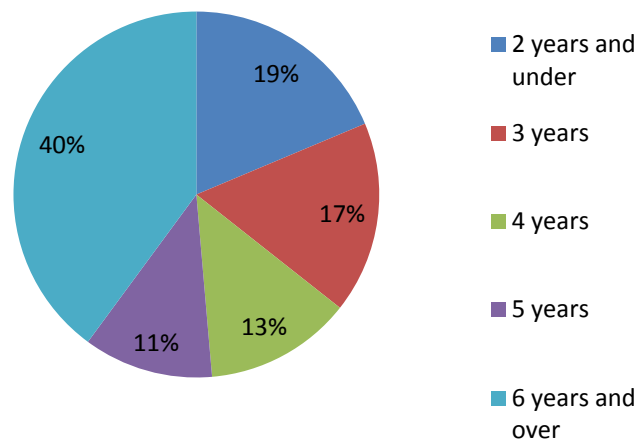


Chart B: National % Parent Learned Diagnosis*



national averages released May 2012 through the CDC (<http://www.cdc.gov/nchs/data/databriefs/db97.pdf>)

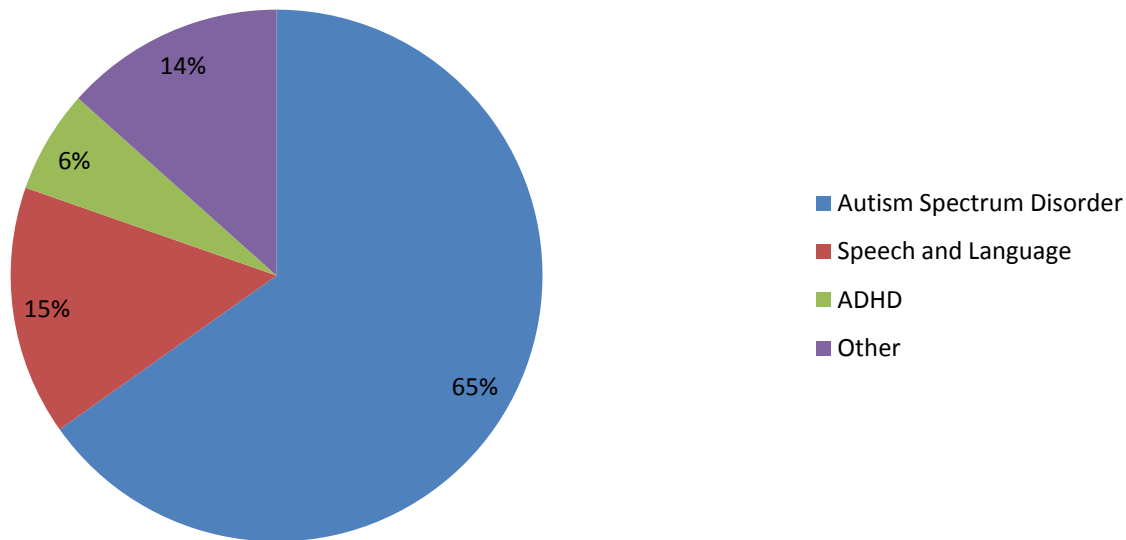




Programmatic Measurement (Example)

98% According to MaineCare Claims Data, Increase
Between 2010 and 2011 in provision of screening for ASD

**Diagnosis Breakdown of Children Referred with
Suspicion of ASD (n=112)**



Legislature – Motivation (Ready?)



Department of Health
and Human Services

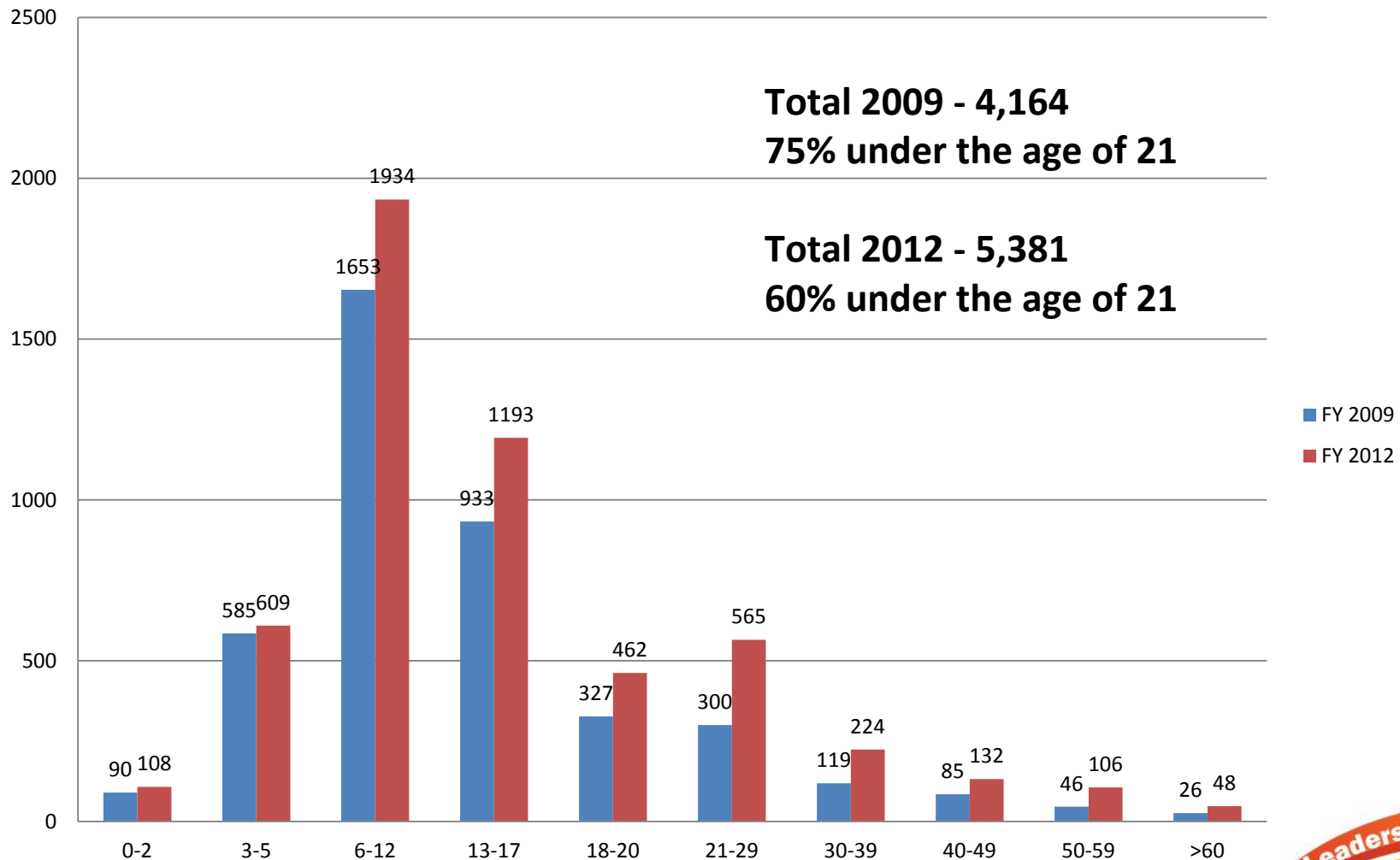
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Autistic Spectrum Disorders Report

In response to legislative directive:
The Autism Act of 1984, 34-B M.R.S.A. §6001



20% Growth Between FY 2009 and FY 2012 in Number of Individuals with an ASD Whose Claims Were Paid Through MaineCare



Data Source: DHHS, Office of MaineCare Services

Prepared By: Maine Developmental Disabilities Council





Thank You

If I can ever be of assistance, please do not hesitate to contact me.

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